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AUTHOR Suelzle, Marijean; Keenan, Vincent
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ABSTRACT

The study examined community based services for developmentally disabled children and their families. A mail survey questionnaire was completed by 66 parents whose children, ages 3 to 21, were attending special schools in a Midwestern suburb. The findings reported are concerned with parents': (1) utilization of primary and professional resources as confidants and consultants, (2) knowledge about services, (3) involvement in service networks, (4) satisfaction with providers, (5) identification of available and needed personal resources, (6) identification of the adequacy of community resources, (7) involvement in the political and administrative processes of service networks, and (8) attitudes toward normalization. The statistical analysis of each question is given. (Author)

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Parents' Perceptions of Community-based Services*

Marijean Suelzle

and

Vincent Keenan

Department of Sociology and Center for Urban Affairs
Northwestern University
Evanston, Illinois 60201

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Introduction

Our society has undergone, and continues to undergo, many changes in attitudes towards and provisions for the developmentally disabled. Throughout most of Western history provision of care and services for such individuals has been the responsibility of the nuclear or extended family. A rural society, wherein families were relatively socioeconomically self-suffient, was conducive to this solution. However, with the expansion of industrialization and urbanization, the services that the family provides for its members, other than the affectional, were transfered to other public institutions (Winch, 1971). Of particular importance, place of work became separated from place of residence, and responsibility was transferred from the home to the school and the employer for increasing portions of a child's education and job training.

The system of public education which developed generalized developmental expectations by age-grade levels. A standardized set of skills were established which all children were expected to attain in order to progress through the system. The developmentally disabled child, who could not attain all of the complex cognitive, physical, social, and emotional developmental skills prescribed, was excluded from the general public educational system. At the same time, the changing social and economic conditions made provision of care and services for the developmentally disabled within the family less viable in an increasingly larger number of instances.

Special institutions for the developmentally disabled, and others who deviated from the "normal," were founded for the purpose of relieving families from the sole responsibility for their care and of

providing the specialized services required. As Wolfensberger (1975:24) states, from reading primary sources around the 1850s, when many institutions were founded, "the goal was a combination of diminishing the intellectual impairment and increasing adaptive and compensatory skills of pupils so that they would be able to function at least minimally in society." Unfortunately, the location of institutions was determined more by economic and political needs than by the needs of the developmentally disabled individuals and their families. The developmentally disabled were aggregated into large multi-purpose (rather than specialized) institutions, often in rural areas, thereby effectively segregating them from their families and their immediate communities. The medical profession became increasingly involved in the administration of these institutions, contributing to our descriptive understanding of the causes and symptoms of developmental disabilities but not to our understanding of the developmental potential of such individuals through education and learning. Developmental goals became replaced by custodial ones.

It was not until the 1950s, with the advent of prosperity following a depression and two world wars, that significant public concern again began to be expressed with equal protection under the law, including better opportunities for the developmentally disabled. Spearheaded by the movement for equality for racial and ethnic minority groups, there followed a recognition of the needs of the developmentally disabled who were also excluded from full participation in our society. Public attention was focused on institutional abuses and, as a consequence, there was a move to return those already in institutions to a life within the community, coupled with a move away from the placement

of the developmentally disabled in large institutions. Despite the change in emphasis from an institutional to a community approach for the provision of services to the developmentally disabled, there has been little emphasis on determining or providing the community supportive services consequently required by developmentally disabled individuals and their families (Grossman and Rowitz, 1973).

In the absence of a comprehensive social system designed to maintain the developmentally disabled as full participants in the community throughout their lives, an obvious place to begin to develop such models is with the actual experiences of families of developmentally disabled persons themselves. As part of a larger project, "Parental choice of services for developmentally disabled children," we have begun to investigate these experiences. This paper is based upon a mail survey questionnaire conducted with parents of children attending three special schools in Evanston, Illinois, a city just north of Chicago. The findings reported are concerned with parents': (1) utilization of primary and professional resources as confidants and consultants, (2) knowledge about services, (3) involvement in service networks, (4) satisfaction with providers, (5) identification of available and needed personal resources, (6) identification of the adequacy of community resources, (7) involvement in the political and administrative processes of service networks, and (8) attitudes toward normalization.

Research Methods

The major portion of the research being conducted for the project, "Parental choice of services for developmentally disabled children" is being carried out in Lake County, Illinois, situated in the north-east

corner of the State. This county has a wide range of services for developmentally disabled persons that includes both residential and community-based programs. Although the County has a diverse population and a wide range of services, the service delivery system is not as complex as that found in Cook County, the large urban area encompassing Chicago, immediately to the south of Lake County. This diversity, with its attendant comparative lack of complexity, has expedited the selection of an appropriate sample of parents and comprehension of the available network of services in use. At the same time an on-going study of early childhood socialization practices in the City of Evanston, situated in Cook County, provided contacts with programs and parents willing to participate in the depth interviews and a pretest of the mail survey questionnaire being developed for Lake County parents. The 57-page survey questionnaire was pretested with parents of children attending three schools for the developmentally disabled in Evanston, Illinois, at the beginning of January, 1978. The questionnaire was sent home in the children's lunch boxes along with a cover letter from the director (at the two private schools) or president of the parents' association (at the public school). Parents were asked to return the completed questionnaire anonymously in an attached self-addressed stamped envelope, and were given about a week to do so.

The participating schools and return rates were as follows: Park School, Public School District #65, 32/59 = 54%; Rimland School for Autistic Children, 14/19 = 74%; and, Shore School (North Shore Association for the Retarded), 18/42 = 43%. An additional 2 questionnaires were returned on which the name of the school was not specified (one question asked for "Name of child's current program or school") for an overall

response rate of 66/120 = 55%.

The returned questionnaires were coded and keypunched and a file defined for statistical analysis of the data with the Statistical Package for the Social Sciences (SPSS) system of computer programs. The data was cleaned by eliminating out-of-range errors and performing a series of contingency checks. The present paper is based upon a preliminary analysis of the results from this survey.

Study Site and Sample Characteristics

With a population of just over 80,000 residents according to the 1970 census, Evanston is a "city-suburb" immediately north of Chicago--"a city in terms of its population, size, and makeup, its form of government, and the social and economic problems it shares with other urban areas . . . a suburb in terms of its physical environment, its relation to Chicago, and the quality of life enjoyed by most of its people" (Squires, 1976:13). But whereas suburbs are often viewed as insulated, isolated pockets of racial and class homogeneity, Evanston's racial and socioeconomic diversity provides a rather clear contrast.

The ethnic and racial diversity of the population has its roots in the early history of the town beginning with the arrival of the first black settler in 1850, but full acceptance into the mainstream of the community was slower in coming. The first black clerk was hired by a department store in 1918, the city's first black alderman elected in 1931, and de facto desegregation in elementary schools voluntarily initiated in 1967. Currently, blacks account for 16 percent of Evanston's population, a proportion which was replicated in our sample (N = 10 out of the 64 respondents providing information on their race; of the remainder, 51 were white, 1 Latino, and 2 Oriental). This is slightly lower than

the Chicago metropolitan average of 17.6 percent shown in the 1970 U. S. Census, but exceeds the national average of 11 percent.

Income levels usually determine many important aspects of family life, such as life style, purchasing power, and whether or not choices of services which are economically feasible exist about which decisions can be made. While reported family income for our sample cannot absolutely be compared to the 1969 family income levels reported in the 1970 U. S. Census for Evanston, both sets of figures do reveal a range on this important characteristic.

Table 1 about here

Marital status also usually determines many important aspects of family life. In general, two parents contribute more interpersonal and economic resources for dependent children than the single parent is able to provide. According to the 1970 U. S. Census, husband-wife families accounted for 84 percent of all families in Evanston, 85 percent in the Chicago metropolitan area, and 86 percent for the country. These figures compare very closely to the 83 percent of our sample respondents reporting themselves as currently married.

Level of educational attainment, however, is not closely matched. The pervasive influence of Northwestern University is reflected in the fact that it is an educated community, where one-third of the people over 25 have completed four or more years of college. The proportion of mothers in our sample having attained that level is even somewhat higher, with 38 percent having four or more years of college. These figures greatly exceed the 1970 U. S. Census report of 12 percent of the people over 25 in the Chicago metropolitan area and 14 percent in

the nation having completed four or more years of college. On the other hand, enough diversity in educational attainment was reflected in the Evanston sample to assure us that the questionnaire could indeed be answered by persons with less than high school graduation and thus would be suitable for the larger and less highly educated Lake County population (see Table 2).

Table 2 about here

Although our sample is clearly not representative on the dimension of education, a possible advantage might be that these parents reflect models who have the ability to evaluate the subjective and objective information available to them and to correspondingly act upon it. Some support for this argument is provided by the fact that almost two-thirds of the sample (65 percent; N = 43) indicated they were "currently a member of a parent group or organization related to developmental disabilities."

The sample of parents reflects the different degrees of disability with which families have to contend. In answer to the question, "Professionals have told me that my child's disability is . . . ," 18 percent reported "mild," 41 "moderate," 34 "severe" and 7 percent "profound." The children's ages span the life cycle: 12 percent preschool (3-5 years old), 40 percent elementary (6-12 years), 34 percent adolescent (13-18 years), and 14 percent young adults (19-21 years old).

Service Network Characteristics

In interpreting the findings from a community study, it is important to consider not only the demographic characteristics of the population and sample compared to other geographical areas, but also the character-

istics of the network of services available in the community. Choices, decisions, satisfaction, and involvement are bound to differ depending upon the relative availability or scarcity of services for the developmentally disabled.

Evanston is a community which is primarily residential in character and whose diverse population requires a wide range of community services, most of which are provided by the local government. The 1960s saw a heightened concern with racial equality and human rights in Evanston as was true in the rest of the nation. This concern was put into action, not only with the voluntary desegregation of the schools, but also by a citizens' vote to tax themselves to provide comprehensive mental health care. A wide range of public health services are provided, including a child health program with the goal of helping

> children realize their full potential for growth and development through a family-centered comprehensive health program. Routine examinations and immunizations are supplemented by parental counseling, nutritional guidance, dental care, and vision, hearing and developmental screening. No fees are charged, and eligibility is determined according to income, with extenuating circumstances taken into account. (Squires, 1976:75)

The Mental Health Services operated as an administrative division of the health department between the approval of the tax levy in 1969 and 1973, when it became an independent service. With the bulk of its budget now spent on contractual services for a variety of agencies, it operates a 24-hour information and referral service which offers help in emergencies and makes referrals to the appropriate agency in non-crisis situations. Evaluation, referral and crisis intervention for the developmentally disabled are included in the comprehensive mental health services network available to Evanston residents.

Evanston is a relatively small city in which a great many people believe that anyone who gets involved and interested in civic affairs can really have an impact. The three special schools through which our mail survey questionnaire was sent to families are all examples of such organized citizen concern and action.

Park School started as a parent-run operation in a private home in 1950, subsequently moving to the Covenant Methodist Church where public school special services staff assumed responsibility for assisting in program planning. When state legislation in 1952 enabled school districts to establish pilot classes for trainable mentally handicapped children, Park School became one of the twelve pilot projects in Illinois. In 1965, the public school district took over full operation of the school, and a new school building was erected in 1968. In addition to the teaching staff, services to children between the ages of 3 and 21 years old are provided by a speech therapist, vocational coordinator, occupational therapist, social worker, psychologist, nurse, special teacher of the multi-handicapped (deaf and hearing-impaired), physical education teacher, and a physical therapist.

Shore School was established at approximately the same time, in 1951, as the North Shore Association for the Retarded. The goals of the school since its inception have been to provide day care services for the severely handicapped to enhance developmental skills, develop pre-vocational skills, and aid in adjustment to community living, as well as offering an alternative to institutional placement. The school presently operates an early childhood intervention program, three workshops, and a community living facility.

Rimland School for Autistic Children was opened in 1971

in the Educational Center of a synagogue by Rosalind Oppenheim, herself the mother of an autistic child. It began with an enrollment of five autistic adolescents, opening an additional classroom of five children each year through 1974, until it now serves the entire 3 through 21 year old age group. The curriculum emphasis--on readiness, pre-school and academic subjects, speech and language training, self-help, self-management, socialization skills, pre-vocational training and gross and fine motor activities, including a swim program and field trips--is more extensively discussed in Oppenheim's Effective Teaching Methods for Autistic Children (1974).

Findings

Confidants and Consultants

Significant others were utilized as sources of emotional support, as confidants (see Table 3) and as sources of information, as consultants (see Table 4).

Tables 3 and 4 about here

As might be expected, members of primary groups are frequently confided in when there are worries about the developmentally disabled child (husbands 77% and friends and relatives 52%, being confided in often). What is perhaps more interesting is that professionals also seem to be operating in this capacity traditionally associated with members of the primary group of extended family (63% often confide in professionals). Conversely, respondents are least likely to keep their worries to themselves (12%).

When advice is sought, as might be expected, health service and edu-

cational professionals are those most likely to be talked to as "expert" sources of information (4/5 would talk to their child's teacher and 2/3 to their child's doctor or another professional such as a social worker or psychologist. Again, what is perhaps more interesting is that parents are next most likely to use as consultants organizations specifically concerned with their child's disability, and other family members and friends. That is, primary group members are as likely to be used as consultants as are formal organizations. Least likely to be consulted for advice are librarians or staff members of a State governmental office. Underutilization of these information sources could result from either a lack of awareness of their expertise or availability, or from negative evaluations of the value to be gained from contacting these sources.

Parents Knowledge About Services

Most parents are unprepared for the birth of a child with a developmental disability (Table 5). Approximately one-half have no prior familiarity with developmental disabilities. Although one-third had known others with disabilities, only one-quarter knew about community resources and only one-seventh had been involved in the field of developmental disabilities.

Table 5 about here

School personnel were relied on most heavily by far when parents selected their children's current school or program, with 64% having done so and being satisfied with the recommendation. About one-half of all parents had visited at least one other school or program first and found it helpful to have done so. About 1/3 were satisfied with

recommendations for social service professionals, doctors, and other parents of developmentally disabled children. Next in order of utilization for information, about one-fifth of parents found it helpful to contact organizations specifically concerned with their child's disability, to get recommendations from family members and friends, and to read materials about options available. Relatively few contacted State officials or religious leaders. In general, parents were overwhelmingly satisfied with whatever source of information they utilized. (See Table 6.)

Table 6 about here

Parents' Involvement in Service Networks

Obtaining knowledge about services available is one of the problems facing the parent of a developmentally disabled child. What happens once parents do become involved in a service network is equally important.

During the visit when doctors first diagnosed their children as developmentally disabled, less than one-half provided information concerning referrals or family support (see Table 7). Doctors are most likely to make referrals to other medical specialists (46%). If support systems are initiated by the doctor, it is most likely to take the form of talking to both parents together (41%). They are next most likely to suggest a prognosis (23%). Referrals, made 20% or less of the time, are most likely to be through more formal channels, that is, to organizations, institutions, or community services. Referrals and recommendations are only infrequently made to disability self-help groups, or for explaining the disability to others (4% in each case).

Table 7 about here

When asked to generalize about all their experiences with doctors, approximately two-fifths (39%) reported that any doctor had ever offered them copies of lab reports or other medical findings. That is, the majority of doctors are not oriented towards providing parents with information on which parents could take the initiative to make decisions and choices. In fact, doctors were as likely to suggest institutionalization (also 39%) as to offer medical information.

Teachers are much more likely to encourage parents to participate in their children's development. Fully 91% were reported as welcoming parents to visit their children's classes (see Table 8). However, interpersonal communication between home and school appears to be an area where there is still room for improvement. Whereas 79% of the teachers offered suggestions to parents, only 60% asked parents for suggestions about how to handle their children. Efforts to both provide parents with more information and to elicit information from them would help involve parents more fully as members of the team.

Table 8 about here

Parents' Satisfaction With Providers

Subsequent medical or professional consultations are frequently necessary to confirm the diagnoses of a developmental disability. Diagnoses and assessments of children suspected of having developmental disabilities often require the cooperation of professionals from different disciplines. Uncertainty about the first diagnosis may be explained by either the medical professionals or parents. Professionals are reluctant to label a delay as a disability until the child is old enough

for it to be obvious that the delay seems permanent. The rates of physical, cognitive, social, emotional and language development can be quite uneven for normal children. Parents may become aware of and concerned about delays which are still within the normal developmental range Parents may become frustrated when professionals are ambivalent about confirming or denying the significance of the delays. On the other hand, parents' love for an individual child may blind them to disabilities which are obvious to professionals. In either case where there is a lack of consensus between professionals and parents, other opinions will be recommended or sought. In the sample, 33% of the parents had changed their children's doctors because of dissatisfaction with the care provided (see Table 9).

Table 9 about here

Most changes of doctors occur for reasons beyond the control of parents--for example, because parents move or a doctor retires (47%), or because a different doctor is more appropriate as children grow older (18%). When changes occur because parents are dissatisfied with the type of care provided by a doctor, the vast majority only change once. There is little evidence of "shopping around." The 33% who had changed due to dissatisfaction represents 22 out of the 66 parents in the sample. Of these 22 parents, 16 changed doctors once, 5 changed twice, and 1 had changed four times. Only 2 parents had to change because a doctor did not want their children as patients, and both had the experience only once.

A substantial majority of parents are satisfied with the existing quality of services: 83% with all the medical professionals their child-

ren currently see, 93% with their children's current schools or programs, and 71% with all the social service professionals currently seen (speech therapist; physical therapist; vocational counselor; social worker; clinical psychologist; family, group or individual therapist; public health nurse; professional homemaker; nutritionist; foster or house parent; genetic counselor).

Parents' Identification of Available Resources and Needs

The isolation of the nuclear family (husband, wife and dependent children) and the burden of responsibility for a developmentally disabled child can be lessened if support networks are available. Natural support networks include grandparents, siblings, other relatives, and friends and neighbors. Professionals augment these natural networks.

The great majority of children are included in everyday family activities. Children are more likely to be excluded, or the family as a unit is less likely to participate, when activities would require group participation of a scheduled duration (i.e., going to movies, sports events, or religious services). (See Table 10.)

Table 10 about here

Having a developmentally disabled child in the family affects mothers and fathers, individually, as well as their marriage. The extra attention that a developmentally disabled child requires can result in either strong bonds of affection or resentment. There may be opportunity costs insofar as the developmentally disabled child requires so many resources--time, energy, money--that other activities have to be curtailed. However, in our sample, most parents did not report feeling adversely affected: 42%

disagreed with the statement, "When I go out, I feel uncomfortable leaving this child at home"; 47% disagreed with "I wish I could go out more alone"; 44% disagreed with "I feel 'trapped' at home."

Grandparents are available to care for children for short periods of time for 71% of the families in our sample. For only 14% were grandparents living but unavailable. For 30% of the families, grandparents were reported as willing to have the children live with them if something happened to the parents.

Significant others, both primary group members and professionals, are utilized to meet the day-to-day management needs of caring for developmentally disabled children (see Table 11). Personal resources--family and friends--are more likely to be used than are community resources such as respite care. Household assistance, where available, is used exclusively through the private sector. Therapeutic counseling and guidance is more likely to be received from professionals than in self-help sessions with other parents (39% versus 27%, respectively). There is a paucity of information sources utilized by families reporting such a need. For example, while only 4% use a parent manual, 74% reported that they would like to do so. (This finding supports the original proposal for the study, which projects a parent manual as one of the products from the project.)

Table 11 about here

Parents' Identification of Adequacy of Community Resources

Parents reflect pessimism or at least uncertainty regarding continued support or expansion of community funding of services for the developmentally disabled. This is not surprising given the general climate of

increasing costs, tax-payers failure to support rate increases which would maintain current levels of services, declining school enrollments, and lay-offs of educational personnel (see Table 12).

Family support services--babysitters, crisis lines, referral services, respite care, homemaker/home-health aides, and counseling--are perceived as extremely necessary but woefully inadequate. Parents perceive a greater need for the expansion or availability of services which would directly benefit their children (babysitters and respite care) than services oriented towards their own needs (crisis lines, referral services, home aides, or counseling services). It is also perceived as necessary to expand educational, living, and community services. Residential and community living facilities are identified as those services most necessary to expand or offer (by 79% and 78% of parents, respectively).

Table 12 about here

Parents' Involvement in Political and Administrative Processes of Service Networks

Parent groups are the single most important factor behind the progress made in recent years in the rights of handicapped children. In Evanston, and across the country, parents were the first to sponsor educational programs for their handicapped children. They fought to get the public school districts to accept their children as students. Since federal legislation (Public Law 94-142) mandates education for all handicapped children three to twenty-one years old, parent groups have taken on the role of monitoring the existing educational, residential and vocational programs. Parents now work to change programming instead of starting new programs. Parents remain an untapped resource, however.

Many parents are willing to take an active role in their children's education because they realize they are the only persons who are in for the duration. They may hesitate to do so because they lack interpersonal experience in organizational involvement, feel overwhelmed by professional expertise, or have difficulty scheduling community activities due to family demands. It is up to professionals and existing parent groups to learn how to engage this willing but underutilized group for the benefit of all the developmentally disabled.

Parents were asked, "In the past year, how often have you attended meetings related to developmental disabilities at which there were other parents present?" At the extremes of participation, only 21% reported that they had never attended any, and 14% reported that they attended meetings more than once a month. The remaining 65% attended, but not as often as monthly.

For many parents, a natural process begins with the identification of their child as developmentally disabled. What starts as self-awareness grows into group social action. First comes the sharing of common concerns and information. More than one-half have participated in group counseling and one-third have participated in educational groups. However, approximately another one-third (32%) report a need for group counseling and nearly another one-half (44%) report a need for educational groups (see Table 13).

Next comes organization to work for expanding and improving community services as well as for the rights and dignity of all developmentally disabled persons. While fewer parents have actively taken this next step, there is a considerable untapped potential here with approximately 1/3 of the parents interested in taking this next step into community

action.

Table 13 about here

Few of the parents in our sample have been involved in the typical political activities which influence local, state, and national policies concerning the developmentally disabled. More have taken individual action (41% have voted for candidates on the basis of rights for the developmentally disabled and 47% have written letters to government officials) than have made a public commitment (20% have attended political meetings and 18% have worked actively for a candidate). But the most striking finding is that fully 50% of parents are willing to make a public commitment although they have not yet done so. This represents an untapped resource of considerable magnitude (see Table 14).

Table 14 about here

Parents' Attitudes Toward Normalization

Theoretically mainstreaming can be conceptualized as a continuum providing developmentally disabled children with an increasing amount of contact with other children. However, parents' attitudes do not seem to be organized in this fashion of increasing or decreasing favorability towards amount of contact provided. Rather, their attitudes are bimodal, favoring either separate buildings or a combination of special and regular classes within a regular attendance center (with 50% and 33% respectively selecting these two alternatives out of four provided as responses to the question, "If your child were to be mainstreamed into the environment which you felt to be most appropriate for his/her developmental disability, which of the following alternatives

would that be?"). Conversely, there is little support for either total integration or for self-contained classrooms within a regular attendance center (with only 2% and 12% respectively selecting these two of the four alternatives).

Attitudes towards mainstreaming are based upon judgments about both the educational and social needs of developmentally disabled children (see Table 15). A majority of parents feel their children learn more in special education classes (83%) and would have difficulty getting along socially if all the other children in the program were normal (59%). On the other hand, nearly one-half (45%) feel their children would greatly benefit from meeting more normal children. This complex assessment of different needs may account for their ambivalence about the motivation for mainstreaming (see last item, Table 15).

Table 15 about here

Discussion

This study has been an attempt to examine community-based services for developmentally disabled children and their families. If the concept of deinstitutionalization is to be recognized in practice, the needs of families must be taken into account. Support must be available over the life cycle or institutionalization will merely have been delayed, not avoided.

Preparation for a future in the community involves more than just keeping a child out of an institution. Preparation for independence must begin early. As one parent said:

> We hope our child will have an opportunity to spend some time during the school day with non-handicapped peers and we are unwilling to lose any services (such as speech

> and O. T.) to accomplish this. We can't see why it should be either/or. If we want our child to live semi-independently in the community, as an adult, we feel he should be learning and playing with non-handicapped children now to prepare him for that.

The normal transition to adulthood for a child in a family involves leaving home to live as self-sufficiently as possible. Developmentally disabled children cannot be graduated from school without the support of continued services throughout their adult lives. Two parents expressed this dilemma very clearly as follows:

> All I can do is hope that if we have her live away from home, she'll be happy. Even if she lives at home she'll probably be a little dissatisfied because eventually all her brothers and sisters will move away. She'll have to depend on community services to provide activities to bring people her age and ability together.

> I am concerned as to his future after he has to leave school at 21. Where will he be? What type of contribution will he be making in the community? Will he still be at home, at a workshop, or living in a residential setting? Also, where are we going to get the money to sustain this young man?

Continued advocacy will be required in order to more clearly define these problems and begin to find some solutions to them.

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Table 1. Distribution of income among families in the Evanston population and sample of families with a developmentally disabled child.

Income Level	Evanston 1969	Sample 1977
$0 - 4,999	10%	5%
$5,000 - 9,999	20	15
$10,000 - 14,999	26	11
$15,000 - 24,999	28	30
$25,000+	16	39
TOTAL	100%	100%
Number of Families	(19,905)	(61)
		Missing Data = (5)

Table 2. Distribution of mothers' education among sample of families with a developmentally disabled child.

Mothers' education	%	(N)
Elementary school or less	4%	(3)
Some secondary school	7	(4)
Senior high school graduate	14	(9)
Some college or university	37	(24)
College or university graduate	14	(9)
Postgraduate study	24	(16)
TOTAL	100%	(65)
Missing data =		(1)

Table 3. Confidants (sources of emotional support). When you are worried about something concerning your developmentally disabled child, how often do you confide in each of the following? (rank ordered by frequency as source of emotional support)

		% Often*
1.	My husband	77
2.	Doctor, minister, or other professional	63
3.	A friend or relative	52
4.	Other parents with developmentally disabled children	37
5.	No one; I keep to myself	12

*N for this and all subsequent tables = 66.

Table 4. Consultants (sources of information).
Parents often react differently to advice depending upon who gives it. If you had a serious decision to make about your developmentally disabled child, would you talk to any of the following? (rank ordered by frequency as source of information)

	% who certainly or probably would
1. Child's teacher	86
2. Child's doctor	65
3. Other professional (such as a social worker or psychologist)	63
4. An organization specifically concerned with your child's disability	56
5. Other family members or friends	50
6. Other parents with developmentally disabled children	39
7. A priest, minister, or rabbi	15
8. Someone in a State governmental office	12
9. A librarian	12

Table 5. Before you knew that your child was developmentally disabled, were you . . .

	% Yes
Acquainted with others who had children with such disabilities?	32
Aware of any community resources available for children with disabilities?	27
Involved in the field of developmental disabilities through volunteer work or college courses?	14
Unfamiliar with both the reality of developmental disabilities and the possibilities of coping with them?	56

Table 6. Before you enrolled your developmentally disabled child in his/her current school or program, did you do any of the following? (rank ordered by frequency of effort to exercise choice)

	% Yes, and helpful
1. Rely on the recommendation of school personnel.	64
2. Visit at least one other school or program first.	52
3. Rely on the recommendation of another professional (for example, social worker).	38
4. Rely on the recommendation of a doctor.	36
5. Ask for or receive any recommendations from other parents of developmentally disabled children.	32
6. Contact an organization specifically concerned with your child's disability	27
7. Ask for or receive any recommendations from other family members or friends.	27
8. Read any materials about options which might be available.	26
9. Ask for or receive any advice from a person working in a state agency.	8
10. Ask for or receive any recommendations from a rabbi, priest, or minister.	3

Table 7. Medical Network Referrals. During this visit [when your child was diagnosed as developmentally disabled], did the doctor suggest any of the following to you? (You may check more than one.)
(Rank ordered by frequency suggested)

	% Yes
1. Referring you to a specialist	46
2. Talking with you and your husband together	41
3. Estimating how far your child would be able to progress	23
4. Referring you to organizations concerned with your child's disability	20
5. Institutionalizing your child, either immediately or in the future	18
6. Choosing a particular therapeutic program for your child (for example, orthogenic, behavior modification, Montessori)	12
7. Explaining the disability to family, friends and others	4
8. Introducing you to other parents of children with developmental disabilities	4

Table 8. Below are some things parents say about meeting with their developmentally disabled child's teacher(s). Do you agree or disagree?

	% Agree
The teacher(s) welcome(s) you to visit your child's classroom or program.	91
The teacher(s) offer(s) suggestions to you on how to handle your child.	79
The teacher(s) ask(s) you for suggestions on how to handle your child.	60

Table 9. How many times have you changed your developmentally disabled child's doctor/pediatrician since your child's birth?

	% who have ever changed
1. Because of reasons beyond your control (e.g., you moved, a doctor retired)	47
2. Because you were dissatisfied with the type of care provided by a doctor	33
3. Because a different doctor was more appropriate as your child grew older	18
4. Because a doctor did not want your child as a patient	3

Table 10. Below are some activities families might do <u>together</u>. Does your developmentally disabled child do the following <u>with you</u>? (rank ordered by frequency of family involvement)	
	% of families who do activity and include child
1. Go for rides in the family car	92
2. Visit friends or relatives	89
3. Take walks, go to beach, or park, or similar activities	89
4. Eat away from home (for example, ice cream parlors, hamburger stands, or restaurants)	89
5. Watch TV	86
6. Go to movies, concerts, plays, sports events, or similar activities	56
7. Go to church or temple (including Sunday School)	47

Table 11. Personal Sources of Support and Needs.
Do you use any of the following to help you take care of your developmentally disabled child?

	% Yes
•Child (day) Care	
Babysitting provided by family and/or friends?	71
Respite care provided by a residential facility?	4
•Household Maintenance	
Regular paid domestic help?	14
Visits by a homemaker funded by the State?	0
•Self-Help/Therapeutic	
"Rap" sessions with other parents of developmentally disabled children?	27
Parent counseling and guidance from agency or school personnel?	39
•Information	
An informal "crisis line" with other parents of developmentally disabled children to provide support in an emergency?	6
A "crisis line" supported by the State for contacting the necessary professionals in an emergency?	3
A parent manual that would identify local, state, and national services available and suggest ways to utilize them?	4

Table 12. Some parents are more satisfied than others with the services that are available to developmentally disabled children in their community. Thinking of your community, please rate the services below according to how important it is to expand or offer them.

	% who perceive need to expand or offer
Family Support	
Babysitters trained to handle developmentally disabled children	83
Crisis lines for parents in times of stress	67
Community referral service for medical and financial contacts, agencies, and parent groups	65
Respite care	74
Homemaker/home-health aides	62
Parent or family counseling services	65
Educational/Diagnostic	
Early intervention programs	62
Diagnostic services and clinics	70
Special education programs	54
Living Alternatives	
Community living facilities	78
Residential facilities	79
Foster homes	53
Nursing homes	42
General Community	
Architectural adjustments made so that it is easier for disabled people to get around	73
Public education concerning developmental disabilities in the news media	71
Reading materials in libraries on child's disability	54
Church services	37
Special buses or vans	47

Table 13. Nowadays there are different types of parent groups. How do you feel about participating in the types of parent groups listed below?

	% who have not, but would like to
Group counseling (where parents meet to discuss their attitudes and feelings toward their developmentally disabled child).	32
Educational group (dealing with techniques of child rearing and development as related to developmental disabilities).	44
Governing or advisory board (dealing with the administration of an organization or facility for the developmentally disabled).	32
Political advocacy group (working to expand options and services for the developmentally disabled).	35

Table 14. Listed below are political activities in which some parents of developmentally disabled children are involved. Have you done, or would be willing to do, the following?

	% who have not but are willing to do
Vote for a candidate you thought would work for the rights of the developmentally disabled regardless of the candidate's party or position on other issues.	29
Write letters to government officials to influence legislation for the developmentally disabled.	38
Attend political meetings to find out candidate's positions on the rights of the developmentally disabled.	50
Work actively for a candidate who supports the rights of the developmentally disabled (for example, passing out leaflets, displaying a campaign poster).	50

Table 15. Some parents have made the following statements about mainstreaming. Do you agree or disagree?

	% Agree
My child learns more in special education classes than would be possible in regular classes.	83
My child would do better in a special recreation program than in a regular program.	77
My developmentally disabled child would greatly benefit from meeting more normal children.	45
My child would have difficulty getting along socially if all the other children in the program were normal.	59
Mainstreaming is an excuse for cutting back funds for special education.	38